

PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT REPRESENTATIVES FOR THE GLOBAL, PAEDIATRIC PLATFORM CLINICAL TRIAL, GLO-BNHL

We are inviting applications from patients, parents/guardians of patients and the public to sit on the Glo-BNHL Trial Steering Committee.

BACKGROUND INFORMATION

Glo-BNHL

The Glo-BNHL trial is trying to find better medicines for children and young people with B-cell non-Hodgkin's Lymphoma (B-NHL) that does not go away (refractory B-NHL) or does but then comes back again (relapsed B-NHL). The medicines used to treat relapsed or refractory B-NHL are very powerful with many side effects and only one in every three children with relapsed or refractory B-NHL are cured with the treatments we have now. It is very important that we quickly find better medicines for these children.

The Glo-BNHL trial is currently in set-up; it will open in at least 17 different countries, with the first hospital planned to start enrolling patients in October 2023. Recruitment will take place over 7 years with a number of different treatments being trialled during this time. The Glo-BNHL trial is being sponsored by the University of Birmingham and the day-to-day activities are managed by the Cancer Research UK Clinical Trials Unit (CRCTU) based at the University of Birmingham.

More information about the Glo-BNHL trial can be found [HERE](#).

TRIAL STEERING COMMITTEE

The Trial Steering Committee includes both independent members and members of the research team and meets to monitor and discuss the progress of the trial. The committee can make recommendations to the Trial Management Group, who are responsible for the day-to-day running of the trial.

It is essential that the committee includes the perspectives of patients and the public. These members of the committee are referred to as Patient and Public Involvement and Engagement (PPIE) representatives.

PPIE representatives are essential because they can:

- consider the perspective of a potential trial participant in a different way to the Trial Steering Committee
- provide a fresh 'critical friend' perspective on the trial design
- offer advice on other planned Patient and Public Involvement in the trial

There are currently nineteen members of the committee, including one PPIE representative. We would like to include another PPIE representative.

More information about the role of PPIE representatives on Trial Steering Committees can be found [HERE](#).

ROLE DESCRIPTION

Responsibilities

- Prepare for and attend Trial Steering Committee meetings, providing a patient/public perspective
- Liaise with the Trial Steering Committee chair and/or the trial management team at the CRCTU by email or telephone between meetings, as required
- On occasion, provide feedback on documents between meetings
- Contribute to discussions and decision-making, respecting the viewpoints of others on the committee
- Maintain confidentiality at all times

Additional Information

- Around 1 hour is required to prepare for each meeting (primarily pre-reading meeting documents, which will be provided at least 1 week in advance)
- Meetings are held monthly and are scheduled for 1 hour, but may be longer
- Meetings are held virtually, with funded opportunities to meet in person on occasion
- Requests may be made to review other documents or participate in other PPIE activities on an ad hoc basis, such as contributing to the creation of documents patients will be given when considering joining the trial
- The role requires an initial commitment of 1 year, with the option to extend throughout the lifetime of the trial
- Applicants must provide information about all potential conflicts of interests, including recent work activities, investments and family connections with the pharmaceutical partners involved in the Glo-BNHL trial
- Expenses are provided for PPIE work as set out below, as per Cancer Research UK guidance:
 - £80 per day (where more than 4 hours is contributed)
 - £50 per half day (where 2-4 hours is contributed)
 - £30 for 20 minutes – 2 hours (including breaks and social time)
 - £5 virtual activity allowance for teleconferences or online activities
 - Reimbursement for reasonable travel expenses, food related to travel for PPIE activities and overnight accommodation (where previously agreed)

PERSON SPECIFICATION

Experience

- Lived experience of cancer (as a patient or family member/carer), or a member of the public who could be affected by the issues being researched
- Participating in formal meetings
- Reading and reviewing written documents
- Working as part of a team
- Public involvement in research (desirable, not essential)

Knowledge

- An understanding of the importance of health research
- A basic understanding of the research process (additional training can be provided)
- An understanding of the importance of public involvement in research

Skills

- Confidence to voice your opinion in group discussions
- Ability to contribute relevant information to group discussions
- Ability to use email, teleconferencing and online meeting software, such as Microsoft Teams or Zoom
- Ability to be objective and consider the needs and opinions of others

Personal Characteristics

- Willingness to share personal experiences
- Willingness to learn and develop in the role
- Reasonable flexibility around meeting attendance
- Willingness to travel on occasion

Learning and Development

- PPIE representatives will receive induction training, to include an introduction to the CRCTU and the Glo-BNHL trial
- PPIE representatives will be assigned a key contact person at the CRCTU to discuss any aspect of involvement in the Glo-BNHL trial
- PPIE representatives will be provided with a PPIE mentor who is an experienced PPIE representative and can provide guidance and support
- The Chief Investigator and other investigators working on Glo-BNHL will provide additional support to PPIE representatives
- Regular training for CRCTU PPIE representatives is scheduled throughout the year
- Additional training can be arranged as required

We are very grateful for the contribution that PPIE representatives make and understand that participation is voluntary. Efforts will be made to ensure that the demands of the role are able to be met without undue inconvenience.